## Testimony of Shannon Flynn Meeting of the Psychopharmacological Drugs Advisory Committee Food and Drug Administration July 19, 2000

My name is Shannon Flynn. I am here today speaking on behalf of the consumer members of NAMI, the National Alliance for the Mentally III. I serve as the chairperson of the Research Committee of NAMI's Consumer Council.

I have been diagnosed with schizoaffective disorder, bipolar type, and have been taking atypical antipsychotics, along with medications to treat mood, for the past nine years. During this time, I have gained an average of about ten pounds per year, which has accumulated to an unhealthy level. Atypical antipsychotic medications seem to have the mechanism of either increasing appetite or decreasing metabolism, an effect I have observed in myself, as well as in the many people with schizophrenia and schizoaffective disorders that I interact with through my support groups and my work. In fact, it is very unusual for me to meet someone with psychotic illness treated with medications who is not overweight, often to a significant degree.

Weight gain caused by atypical antipsychotics increases risk for serious physical illnesses such as heart disease and diabetes, both of which can have fatal consequences. And it can be just as risky to decide to stop taking these medications and possibly face severe decompensation, since weight gain is also a prominent reason for noncompliance. The atypical antipsychotics are tremendously efficacious drugs in terms of symptom relief, both positive and negative symptoms, and in general they have a better side effect profile except for the greater incidence and amount of weight gain, compared to typical antipsychotics.

I have managed to live successfully with my schizoaffective disorder, thanks to my own efforts, the care of a superb psychiatrist, the support of my family and friends, and of course, extremely effective medications. I have a full-time job and a Master's degree in art therapy, facilitate two support groups, and serve on the NAMI Consumer Council in an executive position. I have warm relationships with my family, close friends, and a significant other. I would like to continue enjoying these aspects of a full life, but without treatment with atypical antipsychotic medications, I may not be able to do this.

I am not a doctor. I can't weigh the details of the medical risks. But I encourage you to consider the changes in metabolism and the weight gain as a common and significant problem of many current medications -- involving both long-term medical risks and shorter term risks of stopping treatment. I would like to be able to consider an option to live an enriching life at a normal, healthy weight - as I did before the onset of my illness - although that option might involve other side effects or risks. Together with my doctor, I would want to assess the benefits and the risks of these different alternatives. If the risk

associated with a novel drug is rare and can be decreased with appropriate screening, I would want to have a choice.

Thank you for the opportunity to speak with you on behalf of NAMI's Consumer members.

## Disclosure statement:

NAMI (the National Alliance for the Mentally III) is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, including schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, anxiety disorders, and the major childhood mental illnesses. Founded in 1979, NAMI has more than 210,000 consumers and family members who seek equitable services, expanded research, and improved treatments for people with severe mental illnesses.

In addition to support from membership dues and contributions, NAMI is supported indirectly, through the NAMI Anti-Stigma Foundation, by unrestricted educational grants from companies in both the pharmaceutical and managed care industries. NAMI has a strict policy of not endorsing specific products. Neither Pfizer nor its competitors have had input into our testimony.